

NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES

STATEMENT OF POLICY ON RELEASE OF HEALTH DATA

This document updates and replaces a document in effect since July 1985 titled “Statement of Policy on Confidentiality Pertaining to the Collection and Dissemination of Health Data by the New Jersey Department of Health”

Prepared by:  
Martha Stanbury M.S.P.H.,  
Chair, Institutional Review Board

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the Health Data Release Policy Committee. They provided essential information and review during the preparation of this document.

Ted Bogue, Office of Emergency Medical Services  
Chet Buzzelli, Division of Long Term Care, Systems Development and Quality  
Pam Costa, Division of Family Health Services  
Sam Costa, Division of AIDS Prevention and Control  
Charles Crowley, Division of Addiction Services  
Virginia Dato, M.D., Division of Health Care Systems Analysis  
Anne Davis, Office of Policy and Research  
Pam Dickson, Office of the Commissioner (No longer with the Department)  
Jerry Fagliano, Division of Environmental and Occupational Health Services  
Mark Fulcomer, Division of Health Care Systems Analysis  
Rick Green, Division of Senior Affairs  
Audrey Keim Division of Management and Administration  
Betsy Kohler, Office of Cancer Epidemiology  
Luke Hilgendorff, Division of Management and Administration  
Donald Lipira,, Division of Management and Administration  
Abate Mammo, Division of Addiction Services  
Rose Marie Martin, Division of Health Care Systems Analysis  
Morley Panyko, Office of Administration and Finance: Senior Services  
Rukmani Ramaprasad, Division of Environmental and Occupational Health Services  
Marilyn Riley, Office of Communications  
Sue Robinson, Division of Long Term Care, Systems Development and Quality  
Darcy Saunders, Division of Health Care Systems Analysis  
Richard Schadl, Division of Addiction Services  
Roger Shatzkin, Office of Communications (No longer with the Department)  
Janet Schoenberg, Office of Cancer Epidemiology  
John Tranotti, Division of Communicable Diseases  
Vince Yarmlak, Division of Health Care Systems Analysis  
Martin T. Zanna, M.D., Office of Planning and Organization Development: Senior Services

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Mary Breckenridge Ph.D., Department of Family Medicine, Robert Wood Johnson Medical School  
George Gay, Chief, Registration Methods Branch, Division of Vial Statistics, National Center for Health Statistics  
Jennifer L. Hass, Director, Information Services and Operations, New Jersey Hospital Association  
Nicholas Wright M.D., Associate Professor, Department of Environmental and Community Medicine, Robert Wood Johnson Medical School

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New Jersey Department of Health and Senior Services:  
Statement of Policy on Release of Health Data

## **PURPOSE**

The purpose of this document is to describe the New Jersey Department of Health and Senior Service's policies on release of health data collected by it and to delineate general procedures for release of these data.

## **INTRODUCTION**

The New Jersey Department of Health and Senior Services (NJDHSS) is the official organization within the State of New Jersey for providing information on a variety of health matters in New Jersey. These matters include: deaths; births; injuries; illnesses; impairments; hazardous exposures; medical, dental, hospital and other health care services utilization; and the facilities and personnel which provide health care services. It is responsible for establishing and maintaining appropriate mechanisms to acquire, produce, and safeguard the confidentiality of accurate information about these matters.

It is the policy of the NJDHSS to make available as much health data as is possible within the restrictions of laws and regulations. Release of aggregate, statistical data and individual health records (with or without individual identifiers) can be for research, legal purposes, personal reasons (e.g., an individual wanting a copy of his or her own record), administrative reasons (e.g., program evaluation or audits), or in response to requests from the media or the public.

Under New Jersey's Public Record Statute N.J.S.A. 47:1A et seq ("Right to Know Law"), data collected by regulation, unless protected by specific program regulations or statutes, must be available for inspection and copying by the public. Program-specific state and federal laws and regulations bar disclosure of personal identifying information associated with the collection of health data. Non-disclosure of this information has also been articulated in Governor's Executive Order #9 of 1964. The NJDHSS recognizes the inherent privacy rights of individuals and also recognizes the need to maintain a proper balance between the right to privacy and society's need for information to guide its activities.

This document delineates the policies and procedures of the NJDHSS that govern the release of health data. Policies address the safeguarding of confidential health information within the NJDHSS, the circumstances under which confidential health information is released, and issues regarding the integrity and accuracy of health data. Because procedures for release of data differ depending on the purpose of the request and the type of data being requested, general procedures for release are described for each of the major types of requests. A list of the principal health data sets covered by this document, that are available electronically and the names and telephone numbers of the Programs to which informational requests should be addressed are attached in Appendix 1. Relevant statutes and regulations as of January 1997 are cited in Appendix 2. Requests for health data that are not covered by this policy will be referred to the Office of Legal and Regulatory Affairs, Office of the Commissioner.

## **DEFINITIONS**

*Confidential information:* Information with identifiers about a living\* individual, when that individual has not given consent to make that information public.

*Confidential record:* A paper or electronic record containing confidential information.

*Individual identifiers:* Those elements of the confidential record that state the name, address, social security number, or other information that exactly identify the subject of the record.

*Confidential data elements:* Data elements which by themselves or in conjunction with other elements in the record could easily lead to the identification of the subject. In addition to individual identifiers, these elements may include exact date of birth, municipality, name of physician, name of hospital, and others; whether these data elements are considered confidential depends on the data set.

*Health data files:* Electronic or paper files that contain health and related information about individuals. They may or may not include confidential data elements..

*Confidential health data:* Health data that include confidential data elements.

*Non-confidential health data:* Health data which do not include confidential data elements .

*Individual elementary data units* The individual records within health data files.

*NJDHSS Programs:* The administrative units in the NJDHSS with primary responsibility for collection, maintenance, and release of health data.

*Qualified personnel:* Those individuals with sufficient training and experience to carry out the responsibilities connected with collection, maintenance, release, or utilization of specific health data files.

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\*Information on the death certificate of a deceased individual is considered confidential, except in some limited circumstances. See following pages for additional discussion.

## **POLICIES ON RELEASE OF HEALTH DATA**

### General policies

\* All health records maintained by the NJDHSS that contain personal identifying information are considered confidential and are generally exempt from disclosure provisions of N.J.S.A. 47:1A et seq. Health records that do not contain confidential data elements are not confidential.

\* Data released by any Program will conform with statutory policy and any specific Program statutes or regulations which provide for data confidentiality.

\* Programs are responsible for developing their own specific written data release procedures within the guidelines of this document. Written release procedures are required to be filed with the following units within the NJDHSS: (1) Office of Deputy/Senior Assistant Commissioner (2) the Office of the Assistant Commissioners in the same organizational division as the program; (3) the Chairperson of the NJDHSS's Institutional Review Board (IRB); (4) the Center for Health Statistics; (5) Communications, Office of the Commissioner; (6) the Office of the Chief Information Officer; and (7) the Office of Legal and Regulatory Affairs.

\* In those instances in which the preparation of a data file for release is based on information supplied by more than one Program, all involved Programs will approve the release.

\* Electronic data files should have up-to-date electronic data retention schedules and written data documentation. It is each Program's responsibility to ensure data quality, data verification, and appropriate documentation of data limitations. Programs should make this information available to users of the data as appropriate, especially when data are subject to significant misinterpretation. Programs have the authority not to release data that are known to have significant inaccuracies; where feasible, inaccuracies must be corrected as promptly as possible so that the data can be made available.

\* Special attention should be given to tabulated data that are published or released if these data have small cells, unusual combinations and multiple descriptions. This is because they can accidentally reveal confidential information. In general, the "Rule of 5" will be applied; that is, cells showing units less than five in number will be aggregated with other cells or not published. The purpose of the "Rule of 5" is to protect the individual who might be identified if data were displayed by single unit. Application of the "Rule of 5" may require masking of row and column totals, as well as cells under 5 in order to protect confidentiality. A detailed description of this potential problem and some illustrations and guidelines for avoiding it are found on pages 15 through 18 of the "Staff Manual on Confidentiality," a publication of the U.S. Government's National Center for Health Statistics (Hyattsville, MD, September 1984). The New Jersey Department of Health and Senior Services' Center for Health Statistics should be contacted at (609)984-6702 for more information.

\*Users of the data are expected to report errors in the data back to the Programs. Users may employ new fields containing corrections to errors. Resultant reports and publications should acknowledge the changes and their relationship to the source data when more than five errors are noted.

\* Users of NJDHSS data will be requested to give the NJDHSS copies of abstracts and publications that use the data, as a courtesy. The NJDHSS welcomes all requests for peer review of documents that use and analyze NJDHSS health data. Under certain circumstances, the NJDHSS may require NJDHSS review before the analyses can be published, as a condition for the release of data; such circumstances will be handled on a case-by-case basis, and will be agreed to in writing by all parties.

#### Maintenance of confidential information within the NJDHSS

\* All health records and data associated with individual identifiers shall be handled as confidential, including storage in locked file cabinets and password-protected computer files with access limited only to qualified personnel authorized by the responsible program. Authorized personnel must receive training in the handling of the data and must pledge to maintain confidentiality. Programs should establish systems for monitoring security of electronic data and paper files under general guidelines provided by Management Information Systems Services, Division of Management and Administration.

\* Programs are responsible for identifying confidential and non-confidential data elements within specific health data sets. At a minimum, individual personal identifiers (name, address, social security number where collected, month and day of birth) will be considered confidential. Programs may identify additional fields as confidential (e.g., municipality) based on their judgement that these fields provide information that could lead to identification of individuals, either directly or by reference to other publicly available information. The reasons for making such decisions will be documented in writing and will be available to users of the data.

#### Authorized disclosure of confidential information

\* Health data that include confidential data elements may be disclosed under the following circumstances:

1. With written consent of the person (or his/her legal designee) who is the subject of the record being requested.
2. To qualified personnel for the purpose of conducting scientific research, after the

research protocol has been approved by the NJDHSS Institutional Review Board (IRB).\*

3. To qualified personnel for the purpose of conducting management audits, financial audits, or program evaluation.

4. To qualified personnel for public health activities mandated by statute or regulation.

5. By order of court pursuant to showing good cause.

\* Special circumstances: death and birth records:

1. Although deceased individuals do not have the same legal privacy rights as living individuals, death certificates are not public records. In lieu of (1) above, under N.J.A.C. 8:2-1.2, release of any death certificate or death certificate data that includes cause of death and medical particulars is restricted to the executor of the estate, surviving spouse or caretaker, parent or other authorized member of the family. Release of confidential data under items 2 - 5 above also apply to death certificate data.

2. The NJDHSS provides copies and birth and death records and electronic data from these records to the National Center for Health Statistics for the purpose of national statistics, under an agreement that includes safeguards to the confidentiality of these records.

3. The NJDHSS, under a written agreement that includes State Vital Records Registrars of all U.S. states and territories, transmits copies of birth and death records to the appropriate states/territories where such records relate to residents of those jurisdictions or persons born in those jurisdictions.

#### Release of non-confidential health data

\*The NJDHSS will release non-confidential health data on request, unless contractual or other agreements or regulations prohibit unrestricted release. Programs responsible for the data must be contacted to determine if there are restrictions and the procedures for obtaining the data.

\* Non-confidential health data are routinely released to federal agencies under a variety of contractual arrangements. For example, most communicable disease data and selected other

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\*The IRB follows federal regulations 45 CFR 46. In the case of requests for death certificates that are not covered under federal regulations 45 CFR 46, the IRB has developed criteria for administrative review of the research by the Bureau of Vital Statistics. Any research using death certificates not meeting the developed criteria is sent to the IRB for expedited or full board review.



illnesses and injuries are reported regularly to the Centers for Disease Control and Prevention.

## **PROCEDURES FOR RELEASE OF HEALTH DATA**

### General procedures

\* Requests from the media for health data should be directed to the Office of Communications and requests from the legislature should be directed to the Office of Governmental Relations through the appropriate Deputy/Senior Assistant Commissioner. Both Offices are in the Office of the Commissioner, NJDHSS.

\* Requests for health data other than requests from the media or the legislature should be made to the Programs responsible for the data. Programs should determine if requests should be routed through the Office of Legal and Regulatory Affairs. Requests for summary data may be made by telephone. However Programs have the option to require written requests. Requests for health data files with individual elementary data units should be in writing, and should state the purpose for which the data are being requested and the individual who will be the recipient of the data.

\*The Program will inform the requester of specific procedures that must be followed to obtain the data. The procedures will vary depending on the kind of data being requested and the type of request (see below).

\* When electronic health data files are released, the Program will supply data documentation and statements of known limitations to the user.

\* When non-confidential health data files are released, the Program will include a statement that says that acceptance of the data obligates the user to: (1) make no attempt to identify individuals or to publish information that could easily lead others to individual identifying information, (2) correctly cite the source of the data in any publications, and (3) re-release the data only with permission of the Program and, as appropriate, the NJDHSS Institutional Review Board .

\* The requester may be required to reimburse the NJDHSS for costs related to the transmission of the requested data, including copying, report generation, programming and/or tape/diskette generation. Programs will set reasonable fees for hourly rates for personnel, computer charges, output/medium, individual copies of records, postage, and other charges.

### Procedures for release of confidential health data

*Release of an individual record to the person (or his/her designee) who is the subject of that record:*

An individual's record may be released with written consent of the person (or his/her legal designee) who is the subject of the record being requested. Standard medical record release forms may be used or, alternatively, a form may be used that is developed in accordance with specific regulatory requirements (e.g. release of records of AIDS/HIV patients requires signature

of a notary public and prohibits re-release).

Applicants for death certificates whose request includes cause of death and medical particulars must complete an application that includes a certification of relation to the decedent.

*Release of health data for research:*

When requesting data for the purpose of research, requests for access to health data with individual identifiers, whether from other Programs within the NJDHSS or from individuals/agencies outside the NJDHSS, must be approved by the NJDHSS's Institutional Review Board (IRB). The IRB is constituted in accordance with federal regulations 45 CFR 46 to ensure the safety, privacy, and informed consent of individuals who are subjects of research studies. Under 45 CFR 46, research is defined as "...a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge." Some categories of research are exempt from 45 CFR 46, such as those designed to study public benefit or service programs; the chair of the IRB is qualified to make this determination. The IRB has established procedures for the review of study protocols. When the study is approved, the researcher is required to sign a "confidentiality assurances form." The Office of Legal and Regulatory Affairs, Office of the Commissioner should be contacted for further information.

*Release of confidential data for audits or program evaluation:*

Requests for these purposes, including those from other governmental agencies, must be approved by the Program and the Program's Division. Personal identifying information should only be released if it is vital to the audit or evaluation. Personnel conducting the audit or evaluation must not directly or indirectly identify the person who is the subject of any record in the report of the audit or evaluation or otherwise disclose the individual's identity in any manner. The "confidentiality assurance form" used for research may be modified for use under these circumstances or Programs may develop their own procedures for obtaining assurances in writing that users of the data will safeguard the privacy of individuals identified in the data.

*Release of confidential data to other programs for public health actions:*

Requests for these purposes must be made in writing. The "confidentiality assurance form" used for research may be modified for use under these circumstances or Programs may develop their own procedures for obtaining assurances in writing that users of the data will safeguard the privacy of individuals identified in the data.

*Release of confidential data by order of court:*

All court orders should be referred to the Office of Legal and Regulatory Affairs, Office of the Commissioner, for processing unless Programs have made other arrangements with that Office.

*Release of confidential data outside of the above conditions:*

Requests for the release of confidential health data outside the conditions described above must be approved by the Commissioner of Health and Senior Services, after reviews by the Divisions and Deputy/Senior Assistant Commissioners and the Office of Legal and Regulatory Affairs. Any such request should be submitted in writing to the appropriate Program, along with a statement explaining why the request cannot be handled through any of the procedures listed above.

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APPENDIX 1: PRINCIPAL ELECTRONIC HEALTH DATA SETS as of January 1997

Maintained by the Division of Health Care Systems Analysis; Center for Health Statistics (609-984-6702)

- Deaths\*
- Births\*
- Fetal deaths
- Abortions
- Behavioral Risk Factor Surveillance System surveys

Maintained by the Division of Health Care Systems Analysis; Research and Development (609-984-7931)

Uniform Bill/Patient Summary (hospital discharge data)

Maintained by the Division of Communicable Disease; Communicable Disease Service (609-588-7535)

- Tuberculosis
- Infectious diseases
- Childhood immunizations/vaccine preventable surveillance
- Sexually transmitted diseases

Maintained by the Office of Cancer Epidemiology; Cancer Registry Program (609-588-3500)

Cancer Registry

Maintained by the Division of Environmental and Occupational Health Services; Occupational Disease Epidemiology and Surveillance Program (609-984-1863)

- Occupational Disease Registries
- Census of Fatal Occupational Injuries
- Registries for occupational lead, mercury, arsenic and cadmium toxicity

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\* Applications for individual death and birth certificates are made to Vital Statistics and Registration (292-8085).

Maintained by the Division of Environmental and Occupational Health Services; Consumer and Environmental Health Service (609-984-2192)

Public Bathing: Deaths and/or Serious Injuries

Maintained by the Division of Family Health Services; Community Health Services ( 609-984-1384)

Childhood Lead Poisonings: (Blood lead reports and environmental investigations)

Maintained by the Division of Family Health Services; Maternal and Child Health Planning and Regional Services (609-292-5656)

HealthStart linked file - MSSD Maternity Services Summary Data for HealthStart Clients  
Newborn Biochemical Screening

Maintained by the Division of Family Health Services; Special Child and Adult Health Services (609-292-5676)

Birth Defects Registry  
Newborn Hearing

Maintained by the Division of Family Health Services; Supplemental Nutrition Program for Women, Infants and Children (609-292-9560)

Pregnancy Nutrition Surveillance System (PNSS)  
WIC Participant Data System

Maintained by the Division of AIDS Prevention and Control; Epidemiological Services (609-984-5940)

AIDS/ HIV Infection Registries

Maintained by the Division of Addiction Services; Data Analysis and Epidemiology Service Unit (609-292-1044)

Alcohol Drug Abuse Data System  
Compulsive Gambling

Maintained by the Office of Emergency Medical Services (609-588-7800)

Trauma Registry (under development)

Maintained by the Division of Senior Affairs (609-292-3766)

Statewide Respite Care Clients  
Alzheimer Day Care Clients  
Adult Protective Services  
Office of the Ombudsman for the Institutionalized Elderly

Maintained by the Division of Consumer Support (609-588-2611/588-7032)

Pharmaceutical Assistance to the Aged and Disabled (PAAD) Claims  
PAAD eligibility  
Lifeline claims  
Lifeline eligibility  
Hearing aid claims  
Hearing aid eligibility  
Home Care Expansion  
Medical Day Care  
AIDS Drug Distribution Program (ADDP)  
(from Medicaid files)  
    Pre-Admission Screening Annual Resident Review  
    Nursing Facility Claims  
    Community Care Program for the Elderly and Disabled  
    Assisted Living/Alternate Family Care

## NJDHSS Statement of Policy on Release of Health Data

### APPENDIX 2: RELEVANT STATUTES AND REGULATIONS

#### Federal Laws and Regulations:

Among the key statutes of the U.S. government that include specific reference to the confidentiality of health data are the following:

- \* Section 308(d) of the Public Health Service Act (42 U.S.C. 242m). Confidentiality protections afforded to the health data acquired by the National Center for Health Statistics supersede any rights granted to the public or to individuals by either the Federal Freedom of Information Act or the Privacy Act of 1974.
- \* Privacy Act of 1974 (5 U.S.C. 552a)
- \* Freedom of Information Act (5 U.S.C. 552)
- \* Confidentiality of Alcohol and Drug Abuse Patient Records, Final Rule August 10, 1987 (42 CFR part 2)
- \* The National Research Act, Public Law 93-348, enacted July 12, 1974. Federal regulations 45 CFR 46 implement this law for the protection of human subjects from research risks and establish the principles for the operation of Institutional Review Boards.
- \* Special Supplemental Food Program for Women, Infants and Children, Section 17 of the Child Nutrition Act of 1966, as amended. WIC Program Consolidated Regulations, January 1995. 246.26(d) Confidentiality. WIC Program - General Administration: Confidentiality USDA FNS, FNS Instructions 800-1.
- \* Health Care Financing Administration: Release of Information: Medicaid (42 CFR 432.306 et seq., and 431.301 et seq.)
- \* Older Americans Act (42 U.S.C. 3001 as amended)

#### New Jersey Statutes

- \* N.J.S.A. 9:6-8.40. "Protective Welfare Laws" (WIC program)
- \* N.J.S.A. 26:1A-37.2. "Information and data confidential; disclosure; exceptions." Exempts disclosure of confidential information procured in connection with research studies approved by the Public Health Council.
- \* N.J.S.A. 26:2-107. "Confidentiality of reports" (New Jersey State Cancer Registry)



- \* N.J.S.A. 26:2-111. “Tests of all newborn infants” (Preventable biochemical disorders - newborn infants)
- \* N.J.S.A. 26:4-41. “Contents of reports secret; exceptions (Sexually transmitted diseases)
- \* N.J.S.A. 26:4-60. “Register of reported cases and examinations; inspections” (Tuberculosis)
- \* N.J.S.A. 26:5C-7. “Record of identifying information; confidentiality” (AIDS and HIV)
- \* N.J.S.A. 26:5C-8. “Disclosure of content of record; consent; conditions” (AIDS and HIV)
- \* N.J.S.A. 26:5C-9. “Disclosure by order of court pursuant to showing of good cause (AIDS and HIV)
- \* N.J. S.A. 26:5C-10. “Confidentiality of record after cessation as patient or participant in program” (AIDS and HIV)
- \* N.J.S.A. 26:5C-11. “Confidentiality of record by recipient of disclosure: (AIDS and HIV)
- \* N.J.S.A. 26:5C-12. “Consent for disclosure of record of deceased or legally incompetent person” (AIDS and HIV)
- \* N.J.S.A. 26:5C-13. “Consent for disclosure of record of minor” (AIDS and HIV)
- \* N.J.S.A. 26:6A-8. “Reporting and monitoring” (Deaths)
- \* N.J.S.A. 26:8-40.21 “Birth defects registry”
- \* N.J.S.A. 26:8-40.22 “Confidential reports of abortions of fetus with or infant affected by birth defect
- \* N.J.S.A. 30:4D-7g (New Jersey Medical Assistance and Health Services Act)
- \* N.J.S.A. 30:4D-20 (PAAD)
- \* N.J.S.A. 30:4D-35 et seq. (Hearing Aid Assistance for the Aged and Disabled)
- \* N.J.S.A. 47:1A, et seq. incorporated the common law right of the public to examine and copy public records. This statute was supplemented by Executive Orders 7, 8, and 9 issued by Governor Richard J. Hughes in 1964, with Executive Order #9 nullifying Orders 7 and 8. Executive order #9 exempted medical records from the disclosure provisions of N.J.S.A. 47:1A. Various documents may also be exempt from this public record statute because they have been designated as confidential documents by another statute including ones listed above.. Thus, while the public has a right to NJDHSS

information, this right is not unlimited under N.J.S.A. 47:1A et seq., and other statutes.

- \* N.J.S.A. 48:2-29.15 (Lifeline Credit)
- \* N.J.S.A. 52:27D-423 (Adult Protective Services)
- \* N.J.S.A. 52:27G-1 et seq. (Office of the Ombudsman for the Institutionalized Elderly)

*New Jersey Regulations*

- \* N.J.A.C. 5:27-1.1 et seq. (Adult Protective Services)
- \* N.J.A.C. 5:100-1.2, 1.6 (Office of the Ombudsman for the Institutionalized Elderly)
- \* N.J.A.C. 8:2A-1.2: “Access to Death Certificates”
- \* N.J.A.C. 8:19-1.6. “Confidentiality of reports” ( Newborn hearing testing.)
- \* N.J.A.C. 8:31B-2.1. “Hospital reporting of uniform bill - patient summaries”
- \* N.J.A.C. 8:43G-2.10. “Information not to be disclosed. (Hospital licensing standards)
- \* N.J.A.C. 10:14-4.2. “Confidentiality and disclosure” (Respite Care.)
- \* N.J.A.C. 10:49-9.4. “Confidentiality of Records” (Medicaid.)
- \* N.J.A.C. 10:69-1.1 et seq. (Hearing Aid Assistance for the Aged and Disabled.)
- \* N.J.A.C. 10:69A-6.11. “Confidentiality and Disclosure” (PAAD.)
- \* N.J.A.C. 10:69B-2.6. “Confidentiality and Disclosure” (Lifeline Credit.)

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